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## Development and Evaluation of a Community Cancer Resource Directory

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The project was supported by grant No. CA 20322 from the National Cancer Institute, Public Health Service.

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### Synopsis .....

*The Frederick Cancer-Related Resource Directory was developed in response to the community's need to be informed about available services for cancer patients. A*

*1-year followup and evaluation was conducted to determine what changes or corrections were needed in the text of the directory and if the objectives of the project had been met. The evaluation survey of the listed resources revealed that a large number of changes in the directory were required. Seventy-eight percent of the respondents replied that at least one change was required in their entry. The followup also revealed that 16 percent of the listed resources knew of at least one referral that they received as a result of the directory listing.*

*The survey of directory recipients indicated that 27 percent of the private practice physicians and 61 percent of the other health-related service providers who have a directory have used it or read through it. Approximately 64 percent of the users have provided clients or patients with information from the directory. Almost half of all respondents replied that, as a result of the directory listing, they had developed closer working relationships with at least one other cancer-related service organization, although the percentage was considerably higher for health-related service providers (51.2 percent) than for private physicians (27.3 percent). More than half of the respondents (58 percent) believed that a simpler directory should be made available to patients instead of or in addition to the providers' directory.*

*Members of the project's multiagency committee became much more aware of the wide variety of cancer patients' needs and available resources. The most beneficial aspect of the project for them was the opportunity to work with persons from other agencies and to develop closer, long-term relationships.*

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CANCER PATIENTS, AS WELL AS other chronically ill persons, need many health-related and social services resources. Typically, these people rely on family, friends, and their physicians to help them meet their needs. The patient, family, and physician may also seek assistance from other health care and social service providers. All of these people recognize their need to know about and make efficient use of available community services. Yet it is extremely difficult to be knowledgeable about cur-

rent particulars of these services and such information as eligibility requirements, contact persons, and hours of service.

Methods most commonly used to remain informed about community services are telephone hotlines, community or interagency councils, and resource directories. However, there is a lack of knowledge regarding utilization of these methods and their effectiveness in meeting the need to be informed.

This paper is a description of the development of a cancer-related resource directory used by health care and social service providers in Frederick, Md. The project was unique in that it was a multiagency collaborative effort, and it included a 1-year followup and evaluation.

## Background

Frederick is a county of 100,000 people approximately 40 miles west of Baltimore and about the same distance north of Washington, D.C. The 245-bed Frederick Memorial Hospital (FMH) is the county's only acute medical care facility, and the approximately 50 members of its medical staff provide the vast majority of medical care in the county. Although Frederick County is considered suburban to Baltimore and Washington, residents tend to rely on local medical care and local health-related social services to meet their needs rather than the resources of the two nearby metropolitan areas.

The Johns Hopkins Oncology Center (JHOC) in Baltimore is the Comprehensive Cancer Center for the State and is responsible for providing technical assistance and consultation in all areas of cancer care and control. Frederick was one of the initial outreach communities to receive assistance from JHOC, and since 1977 Frederick Memorial Hospital and JHOC have collaborated on many cancer control projects.

During the initial 2 years of FMH-JHOC collaboration in 1978-79, four surveys were completed to acquire information about organizations and persons of importance to health programs and their interrelationships, as well as to learn of existing resources, programs, and perceived needs and problems related to cancer control in the community. Those survey results are reported elsewhere (1,2).

An important conclusion from the survey data was the confirmation that no formal organized health care system existed in Frederick. Many elements of a community cancer control program were available, yet they were not connected in any systematic fashion. Community leaders, the population at large, and the local physicians also identified multiple areas where additional programs or services were needed. In addition, the surveys revealed a significant lack of awareness and under-use of existing services.

The findings were brought to the attention of community leaders and key persons involved with cancer patients at a special meeting planned by JHOC and the local chapter of the American Cancer Society. It was the general consensus of the participants at the September 1979 meeting that the needs identified by the surveys were being addressed to a greater or lesser degree by currently available programs, but the programs certainly could be enhanced by additional resources. Most of the

*'An important conclusion from the survey data was the confirmation that no formal organized health care system existed in Frederick. Many elements of a community cancer control program were available, yet they were not connected in any systematic fashion.'*

discussion during the meeting centered on the participants' need to communicate with each other, coordinate services among the various agencies, and remain informed about available services and current cancer-related issues. Specific project possibilities were discussed, although no commitments were sought at that time.

Participants were re-contacted later to obtain their impressions of the meeting, assess ongoing interest, and determine who would be willing to work on specific projects. As a result of these discussions, three projects were selected for action: a demonstration cervical and breast cancer screening project, the development of a local telephone cancer information service, and the development of a resource directory. Each project was definable, had a tangible outcome, could be achieved in a specified period, involved more than one agency and, finally, had the potential of providing data to document additional program needs. In this paper we discuss the Frederick Cancer-Related Resource Directory and the evaluation of its usefulness and effectiveness in meeting the intended objectives.

## Development of a Resource Directory

The directory committee, formed in February 1980, included representatives of the major agencies serving cancer patients: health department, department of social services, American Cancer Society, and Frederick Memorial Hospital. The cancer program nurse from FMH and the community programs coordinator from JHOC served as project coordinators. Private oncologists, a cancer patient, representatives from the United Way, Health Systems Agency, Cancer Communications Network Office, and additional JHOC staff members served as consultants.

The objectives of the project were the following:

1. to develop a comprehensive inventory of existing cancer control programs and related services to meet needs experienced by the public, patients, and professionals.

*A surprising 78 percent of respondents reported that at least one change or correction was needed in the directory entry at the 1-year evaluation. Most were in the description of services.*

2. to identify areas where resources are limited or not available.

3. to increase the awareness of health care and social service professionals about existing services available to cancer patients.

4. to increase appropriate utilization of existing services.

5. to increase coordination and communication among the agencies and persons concerned with cancer control and cancer care.

The directory was designed to be used by physicians, nurses, social workers, and other health care and social service providers in a position to link cancer patients with appropriate community resources. Proprietary, non-profit, conventional, and alternative resources were identified. A Prevention and Detection Section was included so that the inventory of cancer-related services would be comprehensive. If a particular resource was not available in Frederick, the next closest and related resource was listed. Also, since the directory was to be used by professionals, information on continuing education and consultation resources was included.

The first 6 months of committee activity were spent organizing and developing descriptions of needs commonly experienced by cancer patients and their families. The purpose of this initial step was twofold. First, members of the committee had the opportunity to discuss needs and problems they encountered among cancer patients. As a result, each person became more knowledgeable and informed about the total needs of cancer patients. Second, most directories are organized alphabetically by agency name, which requires readers to search from beginning to end to find the services they need. A directory organized according to specific patient needs was believed to be easier to read and use.

A comprehensive list of 59 specific needs in eight categories was compiled: prevention and detection, diagnosis and treatment, patient management-physical, emotional and educational, social, home-related, rehabilita-

tion, and financial and legal. An introductory section describing the needs was prepared for the directory for persons who may not be familiar with all aspects of cancer control and the special needs of cancer patients and their families.

The second step in preparing the directory was brainstorming to identify all resources known to committee members and consultants. These brainstorming sessions, which took a period of 3 months, yielded a comprehensive list of resources (public and private, formal and informal). No one person or survey could have uncovered all these resources.

Next, questionnaires for interviewing contact persons were developed and pretested. As a result of the pretesting step, several questions were reworded so that complete information about available resources was obtained.

The interviewing of resource contact persons and writing the text of the directory took 6 months. Most contact persons were telephoned first, informed of the project, and interviewed to determine the nature and scope of their services. A followup questionnaire was mailed to obtain more detailed information. A draft description used these headings: name, address, telephone, hours, contact person, description of services, availability, eligibility, and cost. To minimize errors, the draft was returned to the contact person for verification.

The directory contained information on a total of 148 programs or resources, which were described and listed by needs category. In many instances, one organization was included in several sections because it offered a variety of services. Also, where appropriate, charts were developed for easy reference.

The directory of more than 200 pages was packaged in a loose leaf three-ring binder with dividers and tabs separating the sections. Two hundred directories with binders and 100 directories without binders were printed at a cost of approximately \$2,500. A directory was mailed to each physician listed in the county telephone book believed to see cancer patients (81 physicians) and to each appropriate resource listed in the directory (51 service providers). The printing and distribution took approximately 3 months. Several organizations requested multiple copies. Also, other people interested in the project, but not service providers to Frederick residents, received directories.

## **Evaluation Process**

The evaluation phase was initiated 1 year after the directories were distributed. A literature review revealed no references describing evaluations of resource directories.

The purpose of our evaluation was to determine what changes or corrections were needed in the text and if the

objectives of the project had been met. Two questionnaires were developed. The first was mailed to each resource listed in the directory along with a copy of the agency's descriptive listing. The respondents were asked to submit changes or corrections in the entry and to indicate if they knew of referrals received as a result of being in the directory.

The second questionnaire was mailed to recipients of a copy of the directory. Considerable time and care was taken to formulate questions that would yield information to determine if the objectives had been met, yet take less than 5 minutes to complete. Only a check or X was required to answer the questions.

## Results

A total of 148 questionnaires were mailed to the resources listed in the directory, and 106 were returned, a 71.6 percent response rate. A second mailing increased the returns to 125, a total rate of 84.5 percent.

In response to "To your knowledge have you received referrals as a result of being listed?" 20, or 16.0 percent, of the agencies replied yes. The 20 were representative of each of the directory's sections.

A surprising number—97 respondents or 77.6 percent—replied yes to "Are there any changes, corrections, or additions to the description of your program listed in the directory?" Most changes were in the description of the services (83 respondents or 30.4 percent). In decreasing order of frequency were the following kinds of changes: address (21.6 percent), contact person (20.0 percent), telephone (17.6 percent), and fees (16 percent). Mentioned least often were the program no longer exists, program name was changed, and program or service had been added (each had 5 respondents or 4.0 percent).

Of 139 questionnaires mailed to the original recipients of the directory 46, or 33.1 percent, were returned after the first mailing. After a second mailing to nonrespondents and an additional 19 persons who had access to the directory, the total response was 96, or 60.8 percent, of the 158 questionnaire recipients.

Of the 96 who returned questionnaires, 34 were physicians in private practice (a 42.0 percent response rate) and 56 were nonphysicians providing services to Frederick County residents (an 80.0 percent response rate). The other six respondents were persons who had a directory but did not provide direct service to Frederick residents.

The major questions posed by this survey and the responses are described in the following section.

**1. Do the recipients use the directory?** Of the 34 responding physicians 22, or 64.7 percent, replied that

they had used or read through the directory. A telephone followup was conducted to determine if the physicians who did not return the questionnaire ever used the directory. Of the 16 physicians contacted (34 percent of the nonrespondents) 2 said that they did not recall receiving the directory, and 12 said that they had not used it. One physician had retired, and another had died. It is reasonable to assume that the nonresponding physicians did not use the directory. Thus, 22 of the 81 physicians who were mailed a directory had used it.

Of the 56 persons providing health-related services to Frederick County residents, 43, or 76.8 percent, said that they had used or read through the directory. Six respondents said that they did not for a variety of reasons. Since there was a high response rate of 80.0 percent, no additional followup was conducted for nonrespondents.

The results presented subsequently are based on the responses of the 22 private practice physicians and 43 health-related service providers who said that they had used the directory (table 1).

Ninety percent of the physicians had used the directory to update themselves on available resources. However, 14 physicians also replied that they used it to provide information to their patients. The percentages are approximately the same for health-related service respondents—93 percent had skimmed or read through the directory, and 65.1 percent had used it to provide information to patients, clients, or someone else.

About half of the respondents used the directory less than once a month, but the health-related service respondents appeared to use it more often (table 1).

The survey also sought to compare usage of the directory with the telephone book or the respondent's personal system of keeping track of resource persons, services, and telephone numbers. Although 40 percent used the directory more often than the telephone book for numbers of cancer-related services, 83.1 percent used it as a supplement to their own system or other resource books. Only 21.5 percent said that they used the directory more often than their own systems.

**2. Has the directory helped recipients provide more information about available resources to their patients or clients?** Respondents were asked to check yes or no to each part of the following question, "As a result of the Directory, I have . . ." with six endings provided (table 2). Eighty-two percent had become more aware of the wide variety of services required to meet cancer patients' needs; 74 percent said they had learned about the resources they had no idea were available; and 74 percent had been able to provide more information about available resources. These high percentages held true for both physicians and other health-related service providers.

Table 1. Recipients' use of the Frederick Cancer-Related Resource Directory, 1-year followup survey

Question and response	Physicians (N=22)		Service providers (N=43)		Total (N=65)	
	Number	Percent	Number	Percent	Number	Percent
Have skimmed or read through the directory:						
Yes.....	20	90.0	40	93.0	60	92.3
No.....	1	4.5	2	4.7	3	4.6
No answer.....	1	4.5	1	2.3	2	3.1
Have used directory to give information to patients, clients, and others:						
Yes.....	14	63.6	28	65.1	42	64.6
No.....	7	31.8	14	32.6	21	32.3
No answer.....	1	4.5	1	2.3	2	3.1
Have used the directory for other than cancer-related needs:						
Yes.....	8	36.4	23	53.5	31	47.7
No.....	11	50.0	18	41.9	29	44.6
No answer.....	3	13.6	2	4.7	5	7.7
Have used the directory:						
More than once a day.....	0	...	1	2.3	1	1.5
1-5 times a week.....	1	4.5	8	18.6	9	13.9
1-2 times a month.....	9	40.9	11	25.6	20	30.8
Less than once a month.....	11	50.0	21	48.8	32	49.2
No answer.....	1	4.5	2	4.7	3	4.6

Table 2. Results of using the Frederick Cancer-Related Resource Directory, 1-year followup survey

Question and response	Physicians (N=22)		Service providers (N=43)		Total (N=65)	
	Number	Percent	Number	Percent	Number	Percent
I have learned about resources I had no idea were available:						
Yes.....	12	54.5	36	83.7	48	73.8
No.....	8	36.4	3	7.0	11	16.9
No answer.....	2	9.1	4	9.3	6	9.2
I have been able to provide more information about available resources:						
Yes.....	16	72.7	32	74.4	48	73.8
No.....	4	18.2	7	16.3	11	16.9
No answer.....	2	9.1	4	9.3	6	9.2
I made fewer telephone calls because the information is contained in the directory:						
Yes.....	11	50.0	24	55.8	35	53.9
No.....	8	36.4	13	30.2	21	32.3
No answer.....	3	13.6	6	14.0	9	13.9
I have felt more comfortable in calling other organizations:						
Yes.....	13	59.1	32	74.4	45	69.2
No.....	5	22.7	6	14.0	11	16.9
No answer.....	4	18.2	5	11.6	9	13.9
I have developed closer working relationships with at least one other cancer-related organization:						
Yes.....	6	27.3	22	51.2	28	43.1
No.....	12	54.5	13	30.2	25	38.5
No answer.....	4	18.2	8	18.6	12	18.5
I have become more aware of the wide variety of services required to meet cancer patients' needs:						
Yes.....	15	68.2	38	88.4	53	81.5
No.....	4	18.2	2	4.7	6	9.2
No answer.....	3	13.6	3	7.0	6	9.2

**3. Has the directory helped the recipients know more about each other and thus helped the coordination services for cancer patients?** Less than half of the respondents (43.1 percent) replied that they had developed closer working relationships with at least 1 other cancer-related organization, although the 51.2 percent of their health-related service providers was considerably higher than the 27.3 percent of private physicians. However, a larger number replied that they were more comfortable in calling other organizations—59.1 percent of the physicians and 74.4 percent of the other service providers replied yes to this question. Nearly 88 percent of the respondents agreed that, in general, resource directories help providers to coordinate resources.

**4. Was the directory format easy to use?** The directory committee had been concerned that the book's length and format may have made it cumbersome to use. However, only three persons said that the directory contains too much information or the format makes it difficult to use.

## Discussion

The Frederick Cancer-Related Resource Directory was a response to the expressed need to be informed about services available for cancer patients. Lack of coordination and little knowledge about available resources was identified by the results of a survey and verbalized by community leaders at a meeting designed to determine what could be done regarding cancer control for Frederick County residents. The community did not want to start new programs before existing resources were used fully and appropriately.

It is important to note that each agency allowed a staff member to participate in the project. Each committee member contributed to the development of the directory in addition to carrying out his or her normal job responsibilities. Although the project took 1½ years to complete, the involvement of key persons in the major agencies serving cancer patients was critical in producing a comprehensive and informative reference book.

Committee members completed a lengthy evaluation form on the directory project. All responded that they had become much more aware of the wide variety of cancer patients' needs and available services and of whom to call for more information. They cited the most beneficial aspect of the project as the opportunity to work with persons from other agencies and develop closer, long-term relationships. The least beneficial aspect was the lengthy period required to complete one project.

A number of unmet needs in the county were revealed in putting together the directory. The greatest one ap-

*'When the project was conceived, leaders in the health and cancer fields stated firmly that the directory would be for providers, not patients . . . yet many people felt that a simple directory should be made available to patients.'*

pears to be the scarcity of informational, rehabilitation, and support groups for cancer patients. The original intent of the project's organizers was to hold a followup community meeting to present the directory and discuss unmet needs and unavailable resources. However, funding ceased, and the followup meeting was never held.

The distribution of the directory could have been improved. About 100 extra directories were printed but not distributed, and approximately three-quarters of the directories mailed to private physicians are not being used. A more selective method of allocating books to physicians might be desirable. In contrast, giving directories to other health-related providers appears to be appropriate. In fact, many agencies requested additional copies.

As mentioned earlier, almost 80 percent of the resources listed reported at least one change or correction in their entry. Since the \$10 direct cost of each directory was high, it was decided to prepare an addendum of changes rather than to revise the entire book. The 15-page addendum was mailed to each directory recipient. After 2 years this method of updating would become cumbersome, and the directory would have to be completely redone. It would have been more economical to develop a less expensive directory that could be updated annually and redone every 2 years.

Directory recipients were also asked if a simple version of the directory should be given to patients instead of, or in addition to, that given to providers. Interestingly, 45 percent of the physicians said yes, 27 percent said no, and 27 percent did not answer. But 65 percent of health-related service providers said yes. When the project was conceived, leaders in the health and cancer fields stated firmly that the directory should be for providers, not patients or the general public. Yet in response to this question, many people felt a simple directory should be made available to patients.

Although many respondents said that they have developed closer working relationships with another cancer-related organization, it is doubtful if the directory caused this to happen. A more likely explanation is that the directory made it easier for those inclined to develop such relationships to do so.

It is difficult to determine in absolute terms the worth of the project. More than 90 percent of respondents ranked the directory at 5 (it has been helpful on occasion) on a scale of 1 to 10. Actually, almost 30 percent ranked it 8, 9, or 10 (10 being the directory was the most useful reference owned). Again, health-related service providers tended to rank the directory higher than the private physicians.

## Conclusion

The evaluation of the Frederick Cancer-Related Resource Directory suggests that the objectives of the project were met. A comprehensive inventory of cancer-related resources was developed, and unmet needs were identified, although not confirmed in any other way. There was an increase in awareness of existing services, coordination, and communication among persons working in cancer control and cancer care. Use of existing services may have increased, since a number of resources said that they had received referrals. However, this is not an accurate measure, and no information was obtained regarding appropriate utilization.

The process of developing the directory fostered closer working relationships among the different agencies serving cancer patients. This multiagency cooperative approach assured that the directory would be useful for a variety of people as well as result in several well-informed individuals.

The results of evaluation also confirmed the difficulty of keeping informed about available resources when so many changes occur in 1 year. Whenever a resource information system is developed, considerable effort should be reserved for keeping it current.

The committee's recommendations and suggestions concerning the process of publishing a community cancer-related resources directory are incorporated in the following list of sequential steps.

## Steps in Producing a Resource Directory

**1. Assess the need for a community directory.** In many communities, resource directories have already been written for specific populations, for example, senior citizens. Also, many information and referral telephone systems have been developed. Consider whether another directory is needed or coordination with an existing information system would be more appropriate.

**2. Form a multidisciplinary and multiagency committee.** This step is crucial. No one person or agency is knowledgeable enough to conduct a project as comprehensive as developing a resource directory.

Objectives of the project should be stated. The question, "Who's going to use the directory?," was directed to us repeatedly. Thus, it is important to establish the intent of the directory and its intended recipients.

**3. Determine the directory's format.** Collect and review a variety of existing directories. Note desirable and undesirable characteristics. Most often a directory is a means to locate a resource to meet a specific need. Thus, a directory organized by needs, with clear headings and dividers, is extremely useful. A table of contents and especially an index are necessary.

**4. Brainstorm all resources known in each category of need.** In this step, cover all possible resources. Many directories include only public and nonprofit agencies and thus have limited usefulness. Consider including private, for-profit, and the less formal resources, such as a person knowledgeable in a particular area or a group that will organize a project to help needy people.

**5. Develop and pretest a survey questionnaire.** Questionnaires should always be pretested to ensure the information desired will be obtained. They should be easy and quick to complete. Questionnaires may be altered depending on the category of resource provider being surveyed. For example, the questions we asked for educational services were different from those we asked providers of patient services. Recipients of questionnaires do not like to answer long forms or questions not directly pertinent to their area.

**6. Interview resources.** An initial telephone contact will ensure cooperation in attaining the desired information. By understanding the project and knowing who is involved, the resource provider will appreciate the effort that is being made and cooperate.

A mailed questionnaire is probably be the most common way of soliciting information. A person-to-person interview is recommended for agencies that provide a variety of services and for agencies or persons you would like to know better. Occasionally a telephone interview will suffice.

**7. Write draft descriptions of resources and send them to a contact person for verification.** The headings we used to describe the resources were name of program and organization, address, telephone, hours, contact (person), description of services, availability, eligibility, information or registration, and cost.

Returning the draft descriptions to the resource providers will ensure that accurate information is printed.

**8. Write the final copy.** The final copy should be in a concise and legible form. We chose to print one resource per page, whenever possible, and to develop charts for easy reference.

**9. Package the directory in a three-ring binder.** A binder allows the user to insert or delete pages to update entries, an important feature for prolonging usefulness.

**10. Distribute the directory to the intended recipients.** We recommend mailing or hand-delivering directories to the intended recipients rather than expecting someone to come pick them up.

**11. Evaluate the project.** A 1-year followup evaluation is recommended for two reasons. First, changes will have occurred in the descriptions of resources, ranging

from new telephone numbers to a change in services. Second, the sponsoring body will want feedback on how useful the directory is, and whether changes in format are desirable.

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## Classification of Reasons Why Persons Seek Primary Care: Pilot Study of a New System

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### Synopsis .....

*In 1978, the World Health Organization formed a group to begin work on the Reason for Encounter Classification (RFEC), which is designed to classify the reasons why patients seek care at the primary level.*

*The relatively simple classification is based on two axes—chapters and components—and uses a three-character alpha-numeric code. Chapters, which are named by body systems or more general terms, are the reasons that health care was sought. Five of the seven components, or subdivisions of chapters, contain rubrics identified by the same two-digit numerical code.*

*A pilot study with a training exercise was carried out in The Netherlands by nine family physicians to confirm the feasibility of using the new classification system in primary care settings. Training consisted of viewing videotapes of encounters and an exercise of coding 76 vignettes by the RFEC. Within 2 months, the physicians in the subsequent pilot study had collected and coded 7,503 reasons for encounters.*

*Results of the pilot study confirm that the RFEC is feasible, easy to use in practice, and different from disease-oriented classifications in its system of classifying the reasons for encounter. The pilot study results have been used to modify the RFEC in preparation for a field trial in ambulatory care settings worldwide.*

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**A**T THE 1978 CONFERENCE ON PRIMARY HEALTH CARE in Alma Ata, Union of Soviet Socialist Republics, the primary health care goal of the World Health Organization (WHO), "health for all by the year 2000," was

conceived (1). It was concluded at the conference that the main social target of governments, international organizations, and the whole world community in the coming decades should be attainment of a level of health for all